

ORIGINAL RESEARCH

The legitimacy of rest: conditions for the relief of burden in advanced dementia care-giving

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Accepted for publication 4 December 2009

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DE LA CUESTA-BENJUMEA C. (2010) The legitimacy of rest: conditions for the relief of burden in advanced dementia care-giving. *Journal of Advanced Nursing* 66(5), 988–998.

doi: 10.1111/j.1365-2648.2010.05261.x

Abstract

Title. The legitimacy of rest: conditions for the relief of burden in advanced dementia care-giving.

Aim. This paper is a report of a study conducted to identify the conditions that favour the relief of the burden of female caregivers of relatives with advanced dementia.

Background. Respite services are a response to caregivers' needs for rest. Although they are wanted and needed services, caregivers do not always have access to or use them. The need for a caregiver-centred approach to relieving the burden of care is a conclusion which respite researchers are increasingly reaching.

Method. Grounded theory was chosen as the research strategy. Twenty-two female primary caregivers of relatives with advanced dementia participated in semi-structured interviews between November 2006 and May 2008 in Spain. Data collection was guided by the emergent analysis and ceased when no more relevant variations in the categories were found.

Findings. While having a rest is legislated as a right in civil and religious laws in family care in Spain, it should meet certain conditions that in the caregiver's eyes legitimate it. In the present study these were: (i) when there is no abandonment, (ii) when others are not harmed, (iii) when having a rest is obligatory and (iv) when having a rest is acknowledged.

Conclusion. Many caregivers experience ambivalence over accepting respite. Nurses should assess caregivers' situations and promote context-specific interventions and a relief of burden free from guilt. Exploration of the conditions that favour the relief of burden within other cultural and caregiver groups is recommended.

Keywords: dementia, family care, grounded theory, informal care, nursing, qualitative research, respite care

Introduction

Increasingly more people are taking care of dependent relatives and family care is attracting the interest of public administrators and professionals (Ryan & Scullion 2000). Studies indicate that the care of chronically ill and older people at home would be impossible without family care. In Europe, more than two-thirds of long-term care is provided by families (Nolan *et al.* 1999, Casado Marín & López i Casanovas 2001), and in the United States of America older people with long-term care needs rely exclusively on family and friends for help (Family Caregiver Alliance 2001). At the same time, women are seen as natural caregivers and are the major providers of long-term care (Graham 1983, Finch 1989, Family Caregiver Alliance 2001, Eurostat 2009).

In Spain, the family is the principal source of care and women are the main caregivers (Garcia-Calvente *et al.* 2004, Instituto de Mayores y Servicios Sociales (IMSERSO) 2005), with mothers and daughters taking on this role, sometimes single-handed (Parés & Vernhes 2005). The progressive ageing of the Spanish population and the two million of people with disability (Puga & Abellán 2004), shows that care for a sick relative will be increasingly *natural* in Spanish family life. The recent legislation on dependency (Ley2006) and the development of support services for caregivers in some autonomous regions (Garcia-Calvente *et al.* 2004) shows the recent policy interest in family care.

Caregivers for people with dementia experience disproportionately higher levels of burden, and have more family conflicts and stress and more serious health problems than caregivers of other people with chronic conditions (Miura *et al.* 2005, Andrén & Elmståhl 2008). Patient problem behaviours and cognitive impairment are consistently linked to both psychiatric and physical morbidity of the caregiver (Ory *et al.* 2000). Caregivers also develop resources and ways to endure stress and frustration (Butcher *et al.* 2001) and are able to regain strength to continue caring (Strang & Haughey 1998, Teitelman & Watts 2004). Researchers have identified a variety of problem-solving, cognitive and stress reduction strategies that caregivers use to cope with their situation (Nolan *et al.* 1996, Grant & Whittell 2003). One of the most helpful responses for dealing with stress is maintaining a little private time (Nolan *et al.* 1996) and taking one's mind 'off things for a while' (Salin *et al.* 2009, p. 497). Caring can also be a source of personal satisfaction (Grant & Nolan 1992, Briggs 1998, Chen & Greenberg 2004) where reciprocity, the relationship with the cared-for person and the meaning attached to caring are key concepts in this satisfaction (Nolan *et al.* 1996).

Background

Respite care is concerned with formal and informal ways of caregivers having a rest, and the term addresses both a service and an outcome (Hanson *et al.* 1999). Respite services are considered central to social support policy for caregivers (Arksey & Glendinning 2007), are a response to caregivers' need for rest (Jeon *et al.* 2005, Lee & Cameron 2005), and clearly support caregivers' stress reduction coping strategies. However, in spite of being wanted and needed services (Lawton *et al.* 1991, Kosloski *et al.* 2001, Lund *et al.* 2005), they are not much used by caregivers (Jeon *et al.* 2005, Lund *et al.* 2005, Robinson *et al.* 2005, van Exel *et al.* 2007) and their benefits are unclear (Stoltz *et al.* 2004). Systematic reviews on their effectiveness have shown that the consequences of respite for caregivers are small and that the evidence is limited and weak (Arksey *et al.* 2002, Mason *et al.* 2007, Shaw *et al.* 2009). Lack of evidence on effectiveness does not necessarily mean that services are ineffective, because the reviews point to methodological weaknesses in previous studies, and to the need for further research and robust evidence (Arksey *et al.* 2002, Mason *et al.* 2007, Shaw *et al.* 2009).

Nevertheless, respite services are seen as unrealized potential (Ryan *et al.* 2008). Barriers to respite services are caregivers' concerns about the quality of the care provided (Twigg & Atkin 1994, Upton & Reed 2005), the bureaucracy that is needed to access them (Winslow 2003, Jeon *et al.* 2005) and their economic costs (Winslow 2003). Women evaluate their need for respite against the guilt they feel for needing it and the benefits or disadvantages that its use would have for the care receiver (Nolan *et al.* 1996). Having time off from caring does not mean having a rest from care-giving – a study has shown that a large proportion of caregivers were only partially or not very satisfied with how they spent their time when respite care was being used (Lund *et al.* 2009).

Researcher constantly voiced the need for services that are flexible and individualized to caregivers' needs (Ryan *et al.* 2008). The need for a caregiver-centred approach to relieve the burden of care, with a focus on their individual needs, is increasingly being emphasized (McGrath *et al.* 2000, Nolan *et al.* 2003, Lund *et al.* 2009). New services that have been implemented show the benefits of this approach (Ryan *et al.* 2008).

Qualitative researchers are focusing on respite as an outcome and are deepening our knowledge about the experience of caregivers' who have a rest (Strang & Haughey 1998, 1999, McGrath *et al.* 2000, Chappell *et al.* 2001, Teitelman & Watts 2004, de la Cuesta-Benjumea 2009).

However, what gives rest to caregivers and under what circumstances this occurs is not fully known.

In the study reported here, the focus was women caregivers of people with dementia. Women caregivers are the most exposed to the burden of care and are the least likely to take a rest (Ducharme & Lévesque 2005, Lund *et al.* 2005, Robinson *et al.* 2005). Dementia in the late stages presents the greatest challenges in terms of burden of care for caregivers. This situation of double vulnerability justifies the attention given to them in this study.

The study

Aim

The aim of this study was to identify the conditions that favour the relief of the burden of women caregivers of relatives with advanced dementia. It is part of a major study into caregiving relief in situations of vulnerability (de la Cuesta-Benjumea *et al.* 2006)

Design

Symbolic interactionism was the perspective that informed the study (Blumer 1969). According to Blumer (1969), social behaviour cannot be understood unless its meaning is considered. Meaning arises out of social interaction, it is context-bound and can change in the light of changing circumstances; hence, the importance of uncovering conditions of the interaction. Grounded theory was chosen as the research strategy, it has its roots in symbolic interactionism (Ritzer 2002) and as style of analysis permits identification of conditions pertaining to a situation. Grounded theory is not a unified method. This study was influenced by the work of Charmaz (2000, 2006) on constructivist grounded theory. Here, the end product is constructed and considered to be 'more like a painting than a photograph' (Charmaz 2000, p. 522). The techniques and procedures described by Strauss (1987) and Strauss and Corbin (1998) were used. Glaser's views on data conceptualization were also very helpful during the process of analysis (Glaser 2002).

Participants

The participants were a purposive sample of 22 female primary caregivers of relatives with advanced dementia recruited via healthcare professionals in primary healthcare centres. Sampling was sequential; initially, caregivers with experience in the care of relatives with advanced dementia

were sought. As the analysis proceeded the emergence of variations was facilitated by seeking caregivers with different kin relationships, levels of education and caregiving situations (see Table 1). Sampling concluded when the categories were saturated. Care receivers were cognitively very impaired, incontinent, incapable of self-care and ambulation, and were totally dependent on their caregivers.

Data collection

Twenty-two semi-structured interviews were conducted between November 2006 and May 2008 in Spain. Interviews lasted 40–90 minutes, were audio taped and transcribed verbatim. Eighteen interviews took place in caregivers' homes, three in a health centre and one in a cafeteria. During interviews caregivers expressed in their terms the experience of rest in caregiving. In nine instances the care recipient was present as the caregiver had to look after them. As data collection proceeded, interviews became more focussed to elicit information on the emerging themes. Shortly after each interview field notes were recorded to register the encounter, and these helped to contextualize the information gathered and enabled proximity to the phenomenon during analysis.

Table 1 Participant demographics ($n = 22$)

Age (years)	
40–50	4
51–60	12
61–70	3
+70	3
Education	
None	3
Primary	11
Secondary	4
Vocational	3
University	1
Residence with sick relative	
Co-resident	15
Non-resident	7
Kinship	
Daughter	16
Daughter-in-law	2
Wife	4
Care-giving situation	
Solo	17
On a rota basis	5
Caring for two relatives at the same time	3
Duration of care-giving	
1–5 years	14
6–11 years	6
≥12 years	2

Data collection took place in three waves; it was guided by the emergent analysis and ceased when no more relevant variations in the categories were found (Strauss 1987, Strauss & Corbin 1998).

Ethical considerations

The study was approved by a university research ethics committee and the management board of the healthcare areas involved.

Data analysis

Constant comparison analysis took place after data were entered into QSR NVivo. Analysis developed in three phases: (i) open coding to elicit codes relating to the conditions that enable caregivers to have a rest, (ii) focussed coding to develop and validate emerging categories and (iii) selective coding to complete and validate links between categories. Following Charmaz's (2006), theoretical sampling took place after focussed analysis to seek for variations in the emergent categories. Hence, first codes pertaining to conditions of *complying with the duty, doing no harm, with the right person and a much needed rest* emerged. Codes were developed, refined, sorted and collapsed to become categories and some were renamed. Open coding continued to elicit further categories and, by comparing them, the core category of *legitimacy* emerged. Data were examined to account for variations, further data were collected and analysed to complete the sub-categories and the condition of *being acknowledged* emerged. Micro-analysis and theoretical sampling enabled saturation of the core category, and selective coding validated it against the data. During analysis, memos were written and the literature consulted to aid conceptualization and to guide theoretical sampling. Diagrams were used to visualize links between categories.

Rigour

Relevance and trustworthiness are pivotal issues for the validity of qualitative studies (Lincoln & Guba 1985, Hammersley 1992). The study addressed an area of concern for caregivers, health professionals and policy makers, hence its relevance. Prolonged field work, the naturalistic methods employed and the concurrence of analysis with data collection promoted the trustworthiness of the study. In order to maximize the trustworthiness of findings, they were discussed with a group of professional providers with expertise in the care of peoples with dementia. Also as

categories emerged, were saturated and validated against data and participants, the study complies with the canons of grounded theory (Strauss & Corbin 1998, Charmaz 2006).

Findings

The conditions that favoured relief of caregiver burden were those that made it legitimate in their eyes. These conditions addressed caregivers' concerns about relinquishing their role.

Legitimacy: conditions for the relief of burden

As participants expressed, dementia care-giving is intense, demands constant surveillance and dedication. A legitimate rest was their main concern in relieving the burden of care. While having a rest is legislated as a right in civil and religious laws in family care in Spain, it should meet certain conditions that in caregivers' eyes legitimate it: (i) when there is no abandonment, (ii) when others are not hurt, (iii) when it is obligatory and (iv) when it is acknowledged as a right. Indeed, family care is not located in the labour market; rather, it is a labour of love (Graham 1983). Therefore the conditions for rest are necessarily different. The conditions that give caregivers' rest legitimacy are presented below.

When there is no abandonment

Concerning their rest, women caregivers made it very clear that their sick relatives came 'first', before all including their own needs, and that one 'never leaves' them alone. This implies that care-giving, differently from other everyday life issues, cannot be postponed or neglected.

The data show that the care of the sick persons must be guaranteed and no harm to them could result from caregivers having a break to rest. If those two requisites are not met, even if the caregiver has the right to rest, it is not legitimate to take it as this would be abandonment of both the sick relative and the duty as caregiver. Hence, the time to relax in caregivers' lives emerges when the working day or shift has finished and the sick relative is at rest. For one woman caregiver, 'This is the best moment of the day'; that is, the moment when duty has been fulfilled and caring goals achieved. One caregiver described the moment as follows:

Until they have not had lunch and I arrange everything, I do not leave. It could be half past two or three o'clock. I decided this, she has to be well fed, to have had her drink, her medication, that both (her parents) are tranquil... then I leave.

In addition to having done the caring work, the sick relative has to be well, sleeping or comfortable. To have a rest when

the care recipient is not well and might need care contravenes a caregiver's sense of duty; the caregiver has to have the certainty that 'she will not be needed' while she is absent, as one participant put it.

By the same token, harm to the sick relative cannot result from the caregiver's absence. Hence, participants leave their sick relative alone only when they know that nothing negative would happen to them:

These two hours (of her absence) my mother is not going to move from there, nothing wrong will happen to her.

When there is a need for the presence of someone else for the caregiver to have a rest, this has to be the right person, that is, someone to whom the care of the sick relative could be transferred safely, and someone whom the caregiver trusts. Intimate knowledge of the cared-for person is essential in family care (Nolan *et al.* 2003); without this knowledge, care-giving is jeopardized and therefore the caregiver's respite could be unjustified. In addition, the caregiver substitute has to possess the qualities of affection and commitment to the care-recipient which are characteristic of informal care (Graham 1983). For this reason, caregivers in this study searched for substitutes among cohabiting relatives, such as spouses, parents and offspring; they searched for those whom they know are 'going to be watchful' and therefore no breach of care nor harm would occur.

If the substitute is to be hired from outside the family, caregivers have to be sure that the sick relative is going to be 'well-attended'; hence, caregivers do not just hand over the care, but for some time keep an eye over the hired person until they feel that the sick person can be left with someone outside the family. Caregivers are, indeed, the referees of standards of care (Twigg & Atkin 1994). According to the present data, the central issue here is that is the caregiver's absence passes unnoticed, that care-giving continues as if the caregiver is present, and no harm results. This explains why the occasions for respite, most frequently quoted in the interviews, are when the sick relative needs only some surveillance or simple care, such as giving 'a snack and water'. Indeed, caregivers take care of themselves provided that their instrumental supports do not present a threat to their cared person's well being (Furlong & Wuest 2008).

Whether the cared-for person is left alone or in the care of others, participants' absences are in physical and temporal proximity; they are *out* but not far away and not for a long time. This enforces the legitimacy of their absence. The conditions of people with dementia might change unexpectedly (de la Cuesta-Benjumea 2004). For this reason, as true instruments of care they are 'at hand' and available

during their time of rest, which they give up if they are called.

In summary, participants' times of rest take place under conditions of no abandonment. Continuity of care, the safety of the sick person and their proximity are the principal ingredients. Having a break cannot imply that they do not meet the obligation of caring that they have acquired for their sick relatives and for themselves. Being a caregiver means to be responsible for the cared-for person (Twigg & Atkin 1994), and this goes beyond fulfilling tasks. The well-being of the sick person, even in the caregiver's absence, is her responsibility and she is accountable for it. Care-giving is something that women do for others to keep them alive and is the expression of gender identity (Graham 1983). To rest without abandoning the cared-for person enables rest from care-giving without damaging caregivers' identity and with no regret: their relatives' needs and their own needs are met. This is highly relevant in dementia care due to the increasing dependence of care-recipients on their caregivers. As this study shows, abandonment in this context takes on many and subtle meanings.

When others are not hurt

In the same way that caregivers' rest cannot imply harm to the sick relative, it cannot imply harm to others, especially caregiver's close relatives. McGrew (1998) explains that daughter-caregivers aim at making care-giving decisions that they can live with; so they struggle to both protect and care for their mothers and families and to protect and care for themselves. Indeed, this struggle is highlighted in this study when the need to rest arises and relatives are the only ones the caregiver can rely on.

Participants gave accounts of safeguarding their families from potential traumatic situations resulting from care-giving. A caregiver, for instance, explained that she attempted to 'separate' her daughter from care-giving, and many others gave examples of how they reserve for themselves the most unpleasant aspects of care-giving, and hide their disgust or their need to rest:

....as I gather that this (going out) is doing badly to my sisters, I tell myself that I do not want to, that I do not need to go out, and this is mostly the reason for not going out.

Participants protect their families from suffering by giving care to their sick relatives. This condition places them at a true cross-road, as close relatives are the chosen substitutes. The desire not to hurt mediates women's moral sense (Carter 2001) and explains why some women caregivers in this study relinquished having a break when the substitute was going to have bad time, or why they waited until they felt the substitute was ready to take over:

... my daughter, before she took the nurse aid course, she did not even get close to her (the care-recipient), but now as she has done this course, it is not hard (care-giving) for her.

When women are confronted with moral dilemmas they try to solve them in such a way that no-one gets hurt, and if necessary they sacrifice themselves without expecting that others will do so (Finch 1989). The need for rest by women caregivers is, in this way, over-conditioned by their gender since it implies renouncement, self-sacrifice and protection of their family members (Twigg & Atkin 1994, Briggs 1998). Hence, to rest while care-giving is seen in terms of social morality, suggesting that a given action is not wrong in itself but because of its consequences (Finch 1989). By reserving the worst parts for care-giving to themselves, women caregivers limit their chances of a true rest.

When it is obligatory

Care-giving for a person with dementia is very intense labour, and participants gave accounts of long working days and occasions when they felt they could not cope with all the work ahead and had to rest:

I sit down because I am worn out; I have to sit for an hour and a half. I need it; I cannot continue because of my legs, I cannot continue any more.

Considering that caring for the sick relative is the priority in participants' lives, to have a rest is justified when it is not chosen but imposed. The data show two kinds of obligations: when the caregiver cannot continue and when there are other duties to attend to. Caregivers gave many examples of having breaks when they reached 'the limit of their physical and mental forces', as a caregiver put it. In this situation, rest takes priority over other personal needs: it is compelled and caregivers are so tired that they only want to lie. Fatigue is a persistent characteristic of family care and is exacerbated in dementia care (Miura *et al.* 2005, Andr n & Elmst hl 2008, Brown & Chen 2008); hence it is possible that participants felt that they had to be able to bear it without complaint until they reached their limits. Otherwise, their gender identity and competence as caregivers could be questioned and their identity threatened. Indeed, Smyer and Chang's (1999) showed that caregivers use respite care when they are exhausted and have to stop. In the same way that disease legitimates absence from work (Freidson 1978), not being able to continue giving care legitimates rest. The problem here is that caregivers must go on to limits that contravene their own health.

On the other hand, coping is a central component of women's roles as housewives and spouses (Popay 1992). As

family care is inscribed in these roles, to rest through obligation does not breach role expectations; when resting aims at doing the care-giving role better, it could reinforce these expectations. Indeed, to rest and 'to continue bearing the situation' is right, as the literature on dementia care asserts (Mace & Rabins 1997, p. 247), and reflects the way healthcare services usually relate to caregivers, where their needs are subordinated to their roles as caregivers (Twigg & Atkin 1994).

To comply with other obligations also legitimates care-givers' absence from care-giving as they are forced by them to be absent rather than choosing this. Obligations range from short exits to do household errands or to see the physician, to longer ones such as spending a morning visiting a son's grave in a cemetery. All these obligations justify to some extent caregivers' absence from the care-recipient, and at the same time present them with opportunities to have a break from care. Meeting other demands and duties balances the limitations imposed by taking a legitimate rest. Hence, caregivers can draw on these if they feel it is necessary. Indeed, one participant openly acknowledged that she 'searches for excuses (minor errands) to go out'. To rest is somehow constructed as a duty.

When it is acknowledged as a right

It has been pointed out that the central moral problem for women is the conflict between oneself and others (McGrew 1998), and this is clearly manifested when it comes to the moment to have a rest. Women in the study gave examples of having to fulfil their role expectations as mothers, housewives and caregivers, and also having to meet their own needs for rest from care:

I found myself taking care single-handed of two (older) people. At this moment I realized and said to myself, Well, my mother is my mother. My mother-in-law has the same right... but who cares about me? Who cares if I have a rest or if I do not have it?

Although participants gave many examples of having support from their families to rest, such as a being encouraged to have a break, being substituted while staying away or being relieved of some care-giving duties, this support is not always present and caregivers ought to claim their rest as a legitimate right. For instance, one participant has to explain to her children that she needs 'a time to rest' and not to be overburdened with their demands that they can solve themselves. Another has to argue with her brother over her rest not being a favour granted by him, but a right she has. Family obligations are guided by moral rules that are interpreted, agreed and acknowledged by family members (Finch 1989). Having a break has to meet the condition that

its legitimacy is acknowledged by others and not just by the carer herself.

Caregiver absence of care could be questioned and criticized by relatives or neighbours, as women caregivers said during the interviews. The way to solve this situation is, as one participant put it is 'to grant to herself' this right without worrying about what others might say. Clearly, if the rest is not legitimate in other's eyes, it has to be legitimate in the caregiver's. She is the one who assesses and judges its rightfulness and hence can have a rest free from guilt:

Yes, it is half an hour and sometimes it is less, but for this little time (of going to a cafeteria) I do not feel guilty nor do I feel detached, because it is as if I went out to buy the bread!

It has been suggested that guilt-free decisions are possible by reframing the moral principle of care and responsibility to include both others and oneself (McGrew 1998). A rest is then clearly legitimated by this moral principle, as the quote shows.

In their care-giving decisions, women confront and challenge their moral selves (McGrew 1998). For this reason, the best conditions for caregivers of people with advanced dementia having a rest are when there is an agreement between them and others that it is morally acceptable to do so.

Caregivers need the support of others, and without their acknowledgement the legitimacy of their rest would be questioned and consequently their identity as caregivers threatened. Care-giving does not suspend the right to rest; it just modifies the conditions about when to take it.

Discussion

Study limitations

The limitations of this study arise from the profiles and situations of the participants. Although it was intended to obtain participants from a variety of social classes to saturate categories theoretically, the majority came from low income households and were educated only to primary school level. While these represent the majority of caregivers in Spain (IMSERSO 2005), the point of view expressed here could be limited. It was not easy for participants to speak of their experiences of rest in a situation of stress and worry about the well-being of their sick relatives, and extensive probing during the interviews was required. Problems in terms of the depth of disclosure may have occurred where the care recipient was present (Lane *et al.* 2003); this occurred during some interviews and could also pose a limitation to the data collected.

Discussion of findings

Previous studies of caregivers' sense of relief have revealed their expectations about their care-giving roles and the relevance of their relationships with the person cared for (Strang & Haughey 1998, 1999, Chappell *et al.* 2001). This study continued this line of inquiry and the category of legitimacy sheds light on respite care and its use by women caregivers. While feelings of guilt about using respite services and asking for help have been highlighted in the literature (Lund *et al.* 2005, Salin & Åstedt-Kurki 2007, Vellone *et al.* 2007), less attention has been paid to situations which reduce that guilt. By introducing the concept of legitimacy, this study deepens our understanding of the complexities around relief of caregivers' burden. Taking a rest should not disregard gender norms concerning the responsibility, duty and obligation that women caregivers inherently have (Finch 1989, Briggs 1998, Carter 2001). When women caregivers have legitimate rest they preserve their identity and take decisions they can live with, namely guilty-free decisions (McGrew 1998). Hence healthcare practitioners' interventions to promote respite services for women caregivers should go beyond information and education (Hanson *et al.* 1999) and consider the conditions that make it legitimate in caregiver's eyes to use these services.

Restrictedness is a term that represents the degree to which a caregiver is unable to leave the cared-for person. The legitimacy of the rival activity is of central importance in the construction of this legitimacy; at the heart of restrictedness lies the sense of being responsible (Twigg & Atkin 1994). The findings of this study are thus of relevance to caregivers who feel a strong sense of responsibility and restrictedness, such as spouse caregivers (Carter 2001), caregivers of children with life-limiting and life-threatening conditions (Eaton 2008), caregivers at the end of life (Brazil *et al.* 2009) and those caring for people with learning disabilities or with mental health problems (Twigg & Atkin 1994).

Care-giving within the family is an essential feature of community care and requires formal support. Public policies to support caregivers are still a pending subject in Spain, and formal support only reaches 6.5% of the households (IMSERSO 2005). The issues of care-giving had been left to the family, and this results in great emotional and social costs to women caregivers (Murillo de la Vega 2000). Relief of caregivers' burden should be at the centre of public policies and should aim at removing situations that, disguised as duty and natural, are exploitative of women and detrimental to family life. The burden of care is nowadays an equality issue (Hirst 2004).

What is already known about this topic

- Although respite services are wanted and needed, caregivers do not always have access to them or use them.
- Respite service providers have tended to exclude caregivers' points of view or consideration of the context where family care evolves, and to consider respite being available as good.
- Women caregivers are the most exposed to the burden of care and are less likely to take a rest.

What this paper adds

- Introduces the concept of legitimacy and deepens the understanding of the complexities around caregivers' relief of burden.
- Taking a rest from care-giving takes place under conditions different from those of market labour.
- Caregivers are only willing to use respite services if they consider that there is no feeling of abandonment, others are not harmed, and the rest is obligatory and acknowledged.
- When women caregivers have legitimate rest they preserve their identity and take guilt-free decisions.

Implications for practice and/or policy

- Relief of caregivers' burden should be at the centre of public policies and should aim at removing situations that, disguised as duty and natural, exploit women and are detrimental to family life.
- Interventions to promote respite services for women caregivers ought to go beyond information and education and take into account the conditions that make it legitimate in caregivers' eyes.
- Nurses in their everyday interactions should legitimate caregivers' need for rest and contribute to its acknowledgement by relatives and significant others before caregiver's health is at risk.

Due to the ambivalence that many caregivers experience over accepting respite (Twigg & Atkin 1994, Arksey & Glendinning 2007), nurses should identify those who need it and make it easier for them to have breaks from caring. They should assess caregivers' situations and promote context-specific interventions and relief of burden that is free from guilt.

Conclusion

In their everyday interactions with caregivers, nurses should legitimate their rest and contribute to its acknowledgement by relatives and significant others before a caregiver's health is at risk. Nurses have a unique opportunity and a privileged situation from which to contribute to the relief of burden in family care and thereby to improve caregivers' quality of life. Further research is recommended with other cultural and caregivers groups to explore the conditions that favour the relief of burden more widely.

Acknowledgements

Thanks to the caregivers who generously shared their experiences and to the primary healthcare professionals who assisted in contacting them. Thanks also to the Department of Nursing at the University of Alicante for supporting the study, to Brenda Roe for the help in editing the paper, and to the reviewers for their useful suggestions.

Funding

The study was funded by the Health Research Found, Programme of Biomedical and Health Sciences Research Promotion. Ministry of Health and Consumer affairs. PI 060005.

Conflict of interest

No conflict of interest has been declared by the author.

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